

# Special Addition



**children with special health care**

**fall/winter 2005**

**A NEWSLETTER FOR MISSOURI FAMILIES**

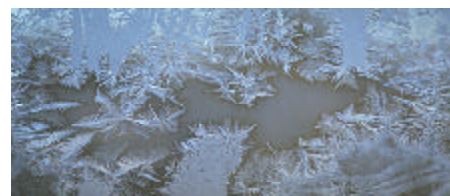
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## **Federal Viewpoint**



### **Have you heard?— the Universal Newborn Hearing Screening and Early Intervention program**

*by Irene Forsman, Health Resources and Services Administration*

*Hearing loss is the most prevalent birth defect. Approximately two to three infants per thousand are born with some level of hearing loss.*

**W**ithin the past 10 years, the percentage of infants screened for hearing loss before hospital discharge rose from less than five percent to 90 percent. Because of technological advancements, hospitals and birthing centers

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## **Local Viewpoint**

### **Local mom receives national mother of the year award**

*by Penny Goff, State News Editor*

**M**alinda Mae Beachum Darter, of New Madrid, MO, recently was the recipient of the

National Mother of the Year award. As one nominator wrote, "Malinda is an exceptionally generous person. She, and her husband, James, have opened their hearts and home to many little ones. Having had and raised one child of their own, the Darters have fostered and adopted a large number of children and provided them with a home filled with love and the kind of caring which many of them had never experienced in their lives heretofore.

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**“There is clear evidence that universal newborn hearing screening substantially lowers the age at which children with congenital permanent hearing loss are identified.”**



Research also shows that infants enrolled in an intensive intervention program by six months of age perform as much as 20 to 40 percentile points higher on school-related measures (reading, arithmetic, vocabulary, articulation, intelligibility, social adjustment and behavior) than children who do not receive such intervention.

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can now easily perform cost-effective physiological hearing screening on all infants before hospital discharge, and therapeutic intervention before six months of age.

Most established programs are able to screen more than 95 percent of all newborns before discharge. Many

states have legislative mandates that require universal hearing screening. Few states, however, include follow-up services, reimbursement, or requirements for reporting and tracking as a part of these mandates.

The Universal Newborn Hearing Screening and Early Intervention (UNHSEI) program funds grants to states for universal newborn hearing screening before hospital discharge, diagnostic evaluation by three months of age, and appropriate intervention services by six months of age. The program reflects expansion of newborn screening and early intervention expressed in Goal #5 of President Bush's New Freedom Initiative (see box on page 7).

### Diagnosis and intervention

There is clear evidence that universal newborn hearing screening substantially lowers the age at which children with permanent congenital hearing loss are identified. Typically, one to three percent of those screened require referral for further diagnostic evaluation and admission into an early intervention program.

Yet appropriate and timely diagnosis and intervention continues to be a major challenge. In the U.S. the average age at which children have been identified with hearing loss is two and a half years, with milder losses

frequently not recognized until a child enters school. In addition, attrition rates as high as 60 percent between initial referral and diagnostic confirmation are still typical. Linkages between screening programs and early intervention programs are not well established. Further, data management and tracking of infants through this process are still in the developmental stage.

### State grants

In April 2000, the Health Resources and Service Administration (HRSA) awarded 22 state UNHSEI grants. In October of 2000, the Centers for Disease Control and Prevention (CDC) awarded 15 state grants to assist with developing Early Hearing Detection and Identification (EHDI) tracking and data management systems. This was the culmination of a concerted effort to promote newborn hearing screening programs using physiologic testing before hospital discharge.

The states use the grant funds to develop statewide systems of newborn hearing screening, audiologic diagnostic testing by three months of age, and enrollment in early intervention programs by the age of six months, with ties to a medical home and family-to-family support services. Currently, HRSA is supporting 53 state/territorial

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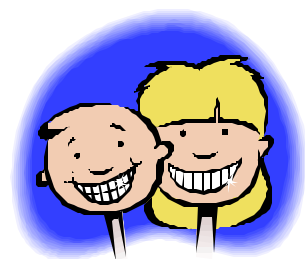


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This is because many of the children for whom Malinda is mother were children no one else wanted or would welcome into their home: children with mental, emotional, or physical afflictions, victims of various kinds of abuse not only in infancy, but even before birth in the wombs of their mothers who harmed their health by the consumption of drugs."

Malinda and James have served as the adoptive parents of 17 children; 13 of which still live in the home. The children are a diverse mixture of races and have various special needs. Malinda believes that parenting is the most important vocation that we choose in our lifetime. She is truly a remarkable woman who has served as a lifesaver for so many children, children who are extremely proud and grateful to be able to call her "Mom."



## Dental health of your special needs child

from: <http://www.saskatoonhealthregion.ca>

A special needs child requires much more from those around him - patience, attention and love. Dental health is one more important need. Often dental care is delayed because of the pressures of more immediate health problems.

A healthy mouth is an important part of total health. It can improve eating, speaking, and how the child looks and

feels about himself/herself. A diseased mouth can cause the following:

- difficulty in chewing and swallowing which can take the pleasure out of eating, and lead to a poor diet
- decayed teeth and swollen, bleeding gums, which are foul smelling, unhealthy, and often painful to the child
- poor speech, which can interfere with school work and making friends.

Dental disease is almost 100 percent preventable. Preventing dental disease is especially important for individuals with special needs. Getting to the dental office can be more difficult, and restoring the mouth is often more complicated. Dentures are not always possible. People with uncontrolled muscle movements may not be able to learn to keep a partial or complete denture in place.

Special needs children are at greater risk for dental disease.

There are a number of reasons why children with disabilities are more likely to have dental disease. Some of these are:

- Oral conditions. Some genetic disorders or very high fevers in young children can cause defects in tooth enamel that make decay more likely. Congenitally missing teeth and teeth that do not align properly are often seen in children with cleft palates. Gum problems often occur in children with Down Syndrome.
- Physical limitations. Children who cannot chew or move their tongues properly do not

benefit from the natural cleaning action of the tongue, cheek, and lip muscles. Children with disabilities, especially those with poor motor coordination (such as spinal cord injuries, muscular dystrophy, or cerebral palsy) may not be able to clean their own teeth or use the usual brushing and flossing methods.

- Special diets. Children who have difficulty chewing and swallowing may often eat puréed foods, which tend to stick to their teeth. Frequent eating of sugary foods or sleeping with a bottle of formula, milk or juice can increase the chances for tooth decay. Children who need help drinking may drink less fluids than other children, so they do not have enough fluids in their mouth to help wash away food particles.
- Medications. Medications using syrup or sugar to sweeten the taste can cause tooth decay if they are taken for a long time. Some anti-seizure medications may cause bleeding or enlarged gums. Excessive gum growth can hamper chewing and speech and lead to gum disease. Sedatives, barbiturates, antihistamines, and drugs used for muscle control may reduce saliva flow. With less saliva, there is less cleansing action to help protect the teeth against cavities. Aspirin, taken in large doses, and dissolved in the mouth before swallowing, can provide an acidic environment that can cause tooth decay. Antibiotics should be

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prescribed cautiously because they can stain or discolour newly erupting teeth.

#### *Diet*

Plaque is a layer of sticky, almost invisible germs that stick to our teeth, gums and tongue. Plaque causes cavities, gum disease and bad breath. Plaque uses the sugar from the foods we eat and drink to make harmful acids. These acids attack the tooth and cause cavities. Sugar is a major cause of tooth decay. The more often you eat sugar and the longer it stays in your mouth, the more harm it can do. To prevent decay:

- avoid sweet snacks, including raisins and other dried fruits that are sticky and high in sugar.
- avoid serving sugary foods. If you serve sugary foods, serve them with a meal when the acid will do less harm.
- read food labels. Look for hidden sugars such as sucrose, dextrose, corn syrup and honey are all sugars.
- offer low sugar substitutes such as cheese, hard boiled eggs, pizza, vegetables, and fresh fruits.
- offer milk, water or vegetable juices instead of sweetened carbonated beverages and fruit drinks.

#### *Fluoride*

Fluoride makes the teeth stronger. Fluoride can be placed on the teeth in a dental office (liquid or gel), and it can be used at home (fluoride tooth-pastes, fluoride mouth rinses and fluoride drops/tablets). Teeth are

protected best when drinking fluoridated water daily.

#### *Sealants*

Another way to prevent tooth decay is to have your dentist paint a plastic coating called a dental sealant on the teeth. Sealants are placed on the chewing surfaces of the permanent molar teeth and bicuspids. This seals the chewing surfaces and protects the teeth from decay.

#### *The Dental Office*

A dental examination is recommended by age one. Many dentists prefer to work with the medical team as soon as a special needs child is born.

Although teeth are not present, this is a good opportunity for the dental staff to provide preventive instruction to the caregiver. Regular dental examinations should continue every year or more often if recommended by the dentist. The dental staff will adapt to the special needs child. For example, the examination area may be modified to accommodate a wheel chair.

Mouth props to help the child hold his mouth open and finger guards to protect the dentist are often used.

Dental care may take place in short time periods. This helps to keep the child's attention and helps her feel less afraid of this new experience. If a child has trouble speaking, seeing or hearing, the dental staff may need to take more time.

Occasionally, it may be necessary to provide dental treatment under general anesthetic in a hospital operating room. Dental treatment done under general anaesthetic has risks. It should be considered carefully before proceeding.

Are you having a problem finding a dentist for your special needs individual? If so, please call 1-800-891-7415 and ask for Cheryl Thomas.

## **YOU HAVE A VOICE**

by Megan Layton

You have a voice  
Let me hear it.  
Don't hold back,  
Don't be shy.  
Just do it.  
You have a voice.

Make them understand it.  
Make them be aware of you.  
Give them your story behind the issues.  
You have a voice.

Belt it out.  
Let everything out and go.  
Be proud that  
You have a voice.

Megan Layton  
Self-Advocate  
Down Syndrome Association  
of Greater St. Louis

## **Missouri notes**

*Occasional thoughts from the Chief of  
Special Health Care Needs*

**W**e live in a world of constant change. In the past several years state government has seen ever-increasing pressure to efficiently serve Missourians while staying within a limited budget. As the new Chief of Special Health Care Needs (SHCN) I am personally committed to meeting these challenges. More importantly, all of the staff of SHCN are committed to continuing to make publicly-funded services work to the benefit of the many adults, children, and family members who are supported by the policy, administration, service coordination, and quality assurance provided through SHCN.

Commitment is an important value and one that all SHCN staff share.

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Everything that we do, from service coordination to administrative processes, is based on a commitment to help people strive for, achieve, and maintain the greatest degree of independence possible. In the future, we will be making organizational changes designed to make the work that SHCN does as streamlined, efficient, effective, and customer-focused as possible. As we move forward, we also plan to listen to suggestions for improvement proposed by the people we serve, and plan to find new ways to hear from them. Missourians impacted by special health care needs bring a sense of directness and urgency to our system that we need if we are to be truly excellent at the work we do. As the SHCN Unit has gone through changes in the past few years, the loyalty, dedication, and commitment of SHCN staff members has become stronger and more resilient. Expect that trend to continue.

In addition to introducing myself as SHCN Chief, I want to mention several other staff members. Diane Poole, former Adult Transition Life-Stage Program Team Leader, was promoted to Associate Unit Chief in July. While continuing to lead the Adult Team, she served as Associate Unit Chief and as Acting Unit Chief. There are not many people who could successfully manage three jobs simultaneously. Diane did a fantastic job. She has also done a great job in orienting me to the unit's operations. Recently, the Brain Injury Association of Missouri recognized Diane with the Point of Light Award. A family member nominated Diane for her contributions to the brain injury community of Missouri.

During the past year SHCN added several new staff members, and promoted others, including: Barlow Biggers (Information Support Coordinator, Jefferson City), Rosilee Duncan (Senior Office Support Assistant, Jefferson City), Melissa Griggs (Adult

Transition Life-Stage Program Team Leader, Jefferson City), Ava Lampe (Senior Office Support Assistant, Poplar Bluff), Tracey Lively (Community Health Nurse, Cape Girardeau), Susan Lopez (Community Health Nurse, Springfield), Judy Miller (Project Specialist, Jefferson City), Kimberly Newkirk (Community Health Nurse, Springfield), Joyce Schulte (Senior Office Support Assistant, Jefferson City), Reantha Seaman (Community Health Nurse, Joplin), and Linda Wilkerson (Health Program Representative, Jefferson City). We are also in the process of hiring an Administrative Office Support Assistant in Jefferson City. This will bring some relief to Kelly Copeland who has been covering for this position while keeping up with her regular full-time duties. Flexibility and mutual support is something that stands out about the people working in SHCN. People provide back up to each other on an almost constant basis, sure evidence that teamwork is part of who we are and getting the job done for the benefit of those we serve is key to our focus and energy.

I am fortunate to have the opportunity to work in this important area and to work with so many dedicated and hard-working people. Diane and I have met with staff and contractors in the regions around the state. I have seen the strong commitment to public service and to the people and families who benefit from the service coordination and administration provided through the SHCN Unit. I have also had the opportunity to meet some of the people we serve. The dedication we see in SHCN staff members and contractors is inspired by the dedication and determination we see in the many Missourians impacted by special health care needs.

As we begin a new year, SHCN staff members look forward to assisting you and your family. If you have questions or need assistance, please feel free to contact us at 1-800-451-0669.

Gary Harbison, Chief, SHCN

## Communicating with people with disabilities

*by Cynthia E. Crawford,  
crawfordc@missouri.edu*

1. Speak directly to the person rather than to a companion or sign language interpreter who may be present.
2. Offer to shake hands when introduced. People with limited hand use or an artificial limb can usually shake hands and offering the left hand is an acceptable greeting.
3. Always identify yourself and others who may be with you when meeting someone with a visual disability. When conversing in a group, remember to identify the person to whom you are speaking.
4. If you offer assistance, wait until the offer is accepted. Then listen or ask for instructions.
5. Treat adults as adults. Address people with disabilities by their first names only when extending that same familiarity to all others. Never patronize people in wheelchairs by patting them on the head or shoulder.
6. Do not lean against or hang on someone's wheelchair. Bear in mind that people with disabilities treat their chairs as extensions of their bodies as do people with guide dogs or help dogs. Never distract a work animal without the owner's permission.
7. Listen attentively when talking to people who have difficulty speaking and wait for them to finish. If necessary, ask short questions that require short answers, or a nod of the head. Never pretend to understand; instead repeat what you have understood and allow the person to respond.

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8. Place yourself at eye level when speaking with someone in a wheelchair or on crutches.

9. Tap a person who has a hearing disability on the shoulder or wave your hand to get their attention. Look directly at the person and speak clearly, slowly and expressively to establish if the person can read your lips. If so, try to face the light source and keep hands, cigarettes, and food away from your mouth when speaking.

- If a person is wearing a hearing aid, don't assume that they have the ability to discriminate your speaking voice.
- Never shout at a person. Just speak in a normal tone of voice.

10. Relax. Don't be embarrassed if you happen to use common expressions such as "See you later" or "Did you hear about this?", that seem to relate to a person's disability.



## Celebrating progress, not perfection

*from [www.driveforrebecca.org/survivalguidefamily](http://www.driveforrebecca.org/survivalguidefamily)*

A critical strategy, which may seem very difficult at times, is to stop comparing our children to other typically developing kids and instead to look at their personal progress.

Every parent has hopes and dreams that their lives would unfold in a certain way. For us, parents of children with special needs, it is easy to look at other kids and families and think of how life could have been, and how far behind and different our children seem.

While we may never be able to overcome all of the feelings of loss, jealousy, or inequality, there are choices that we can make about how we deal with our situations to gain a more positive outlook, and appreciate what we have been given.

The reality of life is that every child is different, and typically developing children are no exception. Some kids naturally excel in certain areas such as academics and sports, and no matter how hard they try, other kids will never come close to matching the achievements of their exceptionally gifted peers. And by constantly comparing average kids to high achievers, the middle of the road children will always come up short.

And the same goes for our kids with special needs compared to other kids their age. We will never appreciate the small progress that our children make if we keep comparing them to others with greater abilities. Our kids are individuals with unique qualities. We will only truly appreciate their special attributes by looking at their progress rather than comparing them to others.

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programs and a national technical support center. These grants are located in 49 states plus the District of Columbia and three US territories (Guam, the Northern Marianas, and Puerto Rico). The national technical support center is the National Center for Hearing Assessment and Management (NCHAM) at Utah State University, under the direction of Karl White, PhD. NCHAM provides nationwide technical assistance and consultation to projects in all of the program areas. These projects, which represent broad geographic distribution, as well as rural/urban areas, all have some level of newborn screening and early intervention activity to date, with the majority of states screening more than 95 percent of infants.

### Two state programs

Kentucky and Massachusetts are just two examples of productive screening and intervention programs. In Kentucky's case, 99.4 percent of all infants born are screened. Of those who fail screening, 4.1 percent are referred to audiologic evaluation. The average age of diagnosis is five months and the average age for early intervention is six months. Most (98.1%) of the infants have a medical home, and Kentucky has a parent-to-parent network group. In addition, Kentucky also uses a state-of-the-art web-based data tracking system.

In the case of Massachusetts, although 99% of all infants are screened, only 1.4% are referred for further audiologic evaluation. Of those referred, the majority (76%) are diagnosed at 3 months or earlier. Like Kentucky, Massachusetts has a family-to-family network. Massachusetts, however, uses the electronic birth certificate to collect metabolic and genetic testing data.

The program enjoys strong support from professional organizations, including the American Academy of

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Pediatrics (AAP). To increase the awareness and involvement of physicians with UNHSEI programs, the CDC and HRSA awarded funding to the AAP for Improving the Effectiveness of Newborn Hearing Screening, Diagnosis and Intervention through the Medical Home. As part of this program, AAP chapters have appointed an EHDI chapter champion as the point person on EHDI-related issues at the state and local levels. Most states have a chapter champion.

Currently, there is limited information that indicates parents and primary care physicians are in favor of screening and early intervention.

Consequently, it is the goal for the AAP chapter champion program to increase the awareness of the newborn hearing screening programs in their states. AAP also plans to expand its outreach to family physicians, public health nurses, physician's assistants, and nurse practitioners.

### Reducing the number who do not seek follow-up services

Although states and hospitals are well on the way to meeting the objective for completing hearing screenings for all infants, national data indicate that nearly half of all newborns who do not pass hearing screening tests do not return for follow-up services (a hearing re-screening, audiometric evaluation, and medical diagnosis). Individual states are using a variety of strategies to mitigate this problem, most of which involve existing public health systems, such as local public health nurses. The collaborative effort with the AAP described above is also expected to reduce the number lost to follow-up.

### Head Start programs

In 2001, the Head Start Bureau initiated an interagency agreement to support a demonstration project of hearing screening in Migrant and American Indian Head Start and Early



“nearly half of all newborns who do not pass hearing screening tests do not return for follow-up services”

Head Start sites in Oregon, Washington, and Utah. In 2002, the three states received supplemental funds to reach out to the Head Start programs to assist in providing follow-up testing, diagnosis, and early intervention services as needed. This has resulted in strong collaborative relationships among service providers in all three states.

To date, more than 100 Head Start staff in 69 program sites have been trained, and 36 pieces of screening equipment have been placed. Screening has been provided to 3,069 infants and children; 171 have been referred for medical and/or audiological diagnosis. Most of the abnormal findings were the result of a process occurring after the newborn period, primarily infection. This project has now been expanded to Kansas and North Carolina. Ultimately, all states will have the option of joining this effort and promoting the concept of early and

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### Title V and President Bush's New Freedom Initiative

Title V of the Social Security Act, revised in 1989, authorized funds for fiscal year 1990 and each fiscal year thereafter for the purpose of enabling each state to provide family-centered, community-based, coordinated care (including care coordination services) for children with special health care needs and to facilitate the development of community-based systems of care for such children and their families.

The Integrated Services Branch (ISB) of Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB), Division of Services for Children with Special Health Needs (CSHCN), which administers this provision of Title V, promotes leadership and support for the development and implementation of innovative, replicable models of community-based care for children with special health needs in six program areas: Medical Home, Family Professional Partnership/Cultural Competence, Financing/Managed Care, Community Integrated Services, Early and Continuous Screening and Early Intervention, and Healthy and Ready to Work.

The primary objectives of the CSHCN program are to fulfill the *Healthy People 2010* goals set under Maternal, Infant, and Child Health (Goal 16-23) and accomplish the following specific goals under President Bush's *New Freedom Initiative*:

1. Development of community-based systems of services that are inclusive of CSHCN and their families, where substantial decision-making authority is devolved from the federal government to the states to the communities.
2. Recognition that families are the ultimate decision-makers for their children and encouragement of participation in making informed decisions.

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continuous screening.

### Further follow-up

The CDC EHDI is currently funding 29 states and one U.S. territory to assist in the development of data surveillance and tracking systems to minimize loss to follow-up. In 2002, the CDC and HRSA entered into an intra-agency agreement to support targeted investigation of the reasons for loss to follow-up in five diverse states. The investigation will be completed in the summer of 2005. Results will be disseminated. In addition, MCHB began a program-wide review of its newborn hearing screening program in the fall of 2004.



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3. Development of standardized elements of the medical home for CSHCN. In addition, the agency will develop and disseminate models of the medical home, and provide additional training resources to primary care professionals to develop medical homes.
4. Review of the variety of reimbursement mechanisms that affect CSHCN.
5. Through the MCHB grant (Title V of the Social Security Act) and the Newborn Genetics program (Title XXVI of the Child Health Act), expansion and strengthening of newborn screening and intervention systems. Promotion of on-going screening of CSHCN.
6. Ensuring that youth with special health care needs receive the services necessary to make the transition to all aspects of adulthood, including conversion from pediatric to adult health care, from school to employment, and then to independence.

## The Missouri newborn hearing screening program

**T**he Missouri Newborn Hearing Screening Program (MNHSP) is a part of continuing national efforts to promote the early detection of hearing loss, the tracking of infants/children who are deaf or hard of hearing, and the initiation of effective intervention systems. In Missouri, hearing screening for newborns became mandatory on January 1, 2002. All Missouri birth facilities screen newborns for hearing loss prior to discharge. If a baby does not pass the screening, the birth facility will provide the parent/guardian with a list of audiologists who can provide diagnostic testing. If hearing loss is found, a MNHSP Regional Representative will refer the infant's parents/guardians to First Steps for appropriate early intervention programs. To contact MNHSP, call Cathy Harbison at (573) 751-6266 or 1-800-877-6246.

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